

Challenges and Strategies for Communicating Science & Technology – A Case Study on AIDS Campaigns of PPWS in Tirunelveli

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Article History

Received: 08.01.2018

Accepted: 20.01.2018

Published: 30.01.2018

DOI:

10.21276/sjahss.2018.6.1.34



Abstract: In India, Tamil Nadu is one of the 6 states which are announced as high risk states. Knowledge and awareness are important factors in preventing HIV/AIDS epidemic. The civil sectors particularly Non-Government Organizations play a key role in creating awareness among the people and make concerted efforts to bring them under the protected umbrella. Tirunelveli being a high risk district of Tamil Nadu, PPWS are functioning at the grass root level. PPWS concentrates mostly on the care and support of the PLWHAs. PPWS are run by the people reported HIV/AIDS. They communicate to the people about the HIV/AIDS, bring awareness among them, volunteer them to report, and encourage them to live with the deficiency with courage. This paper is aimed to study the strategies and challenges facing in communicating HIV/AIDS by the PPWS. This paper presents the communication strategies including organizing health camps, street theatres, Exhibitions and participatory approaches and creating awareness through group discussions employed by the PPWS. The PPWS concentrate not only creating awareness about HIV/AIDS and also provide psychological counseling. In-depth interview method is employed in this study.

Keywords: AIDS Campaigns, Tamil Nadu, PPWS, psychological counseling.

INTRODUCTION

India has large number of people living with HIV/AIDS, which is estimated to be 5.134 million in 2004. In India, Tamil Nadu is one of the 6 states which are announced as high risk states. Even after an increase in the level of awareness about AIDS in India, Tamil Nadu is still among the six high-prevalence states in India, with major challenges being lack of awareness, social stigma related to AIDS/HIV and youngsters remaining reluctant to test themselves for AIDS, says officials at Tamil Nadu State AIDS Control Society (TANSACS) [1].

Every year more than four lakh people are tested and counselled for HIV in Tamil Nadu. According to NACO till July 2005, 52,036 AIDS cases were reported in Tamil Nadu. Tirunelveli is one of the high-risk districts in Tamil Nadu. The civil sectors particularly Non-Government Organizations play a key role in creating awareness among the people and make concerted efforts to bring them under the protected umbrella. It is essential to know the strategies and challenges in communicating HIV/AIDS. To get an overview, we done a case study.

Tirunelveli being a high-risk district of Tamil Nadu, PPWS is one among the NGOs are functioning at

the grass root level. PPWS (Positive People Welfare society) concentrates mostly on the care and support of the PLWHAs. The people living with HIV/AIDS run this PPWS. They communicate to the people about the HIV/AIDS, bring awareness among them, and volunteer them to report, and encourage them to live with the deficiency with courage. They are fighting against stigma and discrimination. PPWS have network throughout Tamil Nadu. PPWS in Tirunelveli is rendering its service throughout the district. In Tirunelveli PPWS, 650 PLWHA have registered till now and nearly 1000 PLWHAs are identified. Hence it is interesting to study the Communication strategies they are using to reach PLWHAs and also the challenges they are facing in communicating HIV/AIDS.

Objectives:

- To study the strategies used in communicating HIV/AIDS
- To study the challenges faced in communicating HIV/AIDS

METHODOLOGY

Case study research refers to “an empirical inquiry that investigates a contemporary phenomenon

within its real-life context" [2] Case study is best used to understand complex social and organizational issues[3]. In this study, we focus on a single NGO PPWS, which works in HIV/AIDS awareness campaigns as an intrinsic case study also our unit of analysis to explore and to gain insight into AIDS/HIV communication. In this study, we used a combination of documents and in-depth interviews to address our two research questions. In-depth interviews provide detailed background and when compared to more traditional survey methods, it provides more accurate responses on sensitive issues[4]. Participants are able to tell their stories and discuss their involvement in detail. In-depth interviews will enable us to better understand the HIV/AIDS communication, the challenges in communicating and the various communication strategies used in communicating HIV/AIDS.

Selection of Respondents and Data collection

There is no firm rule on a recommended sample size, but McCracken [5] indicates that recruiting eight respondents is generally sufficient for many in-depth interview projects. Hence we follow that and interviewed eight respondents that included -

Findings

HIV positive certainly does not mean death. It has taken a decade for him to come out of seclusion and tell the world without hesitation, "I'm HIV positive." Now he speaks at meetings and organises awareness programmes for his ilk and urges them to face the grim reality. "If I can live, so could you," he tells them. Being one of the thousands of 'survivors' who live with hope, Kumar's words carry much conviction.

At the age of 24, while trying for a job abroad, Kumar was found to be HIV positive and he felt the whole world had come down upon him. For seven to eight years, he went into a self-imposed seclusion, shunning family members and relatives. He dared not step outside the room and hit the bottle, haunted by constant fear of death, health problems and above all neighbors' taunting comments.

Kumar rewinds his past: "There was not much awareness then. I was in Mumbai, working as a mechanic in a reputed company. Being away from home, especially with lot of money and age factor, I enjoyed my life to the core without being aware of the impending danger in store."

More positive messages

The real killer is not the virus but the stigma and discrimination attached to it. The need of the hour is not only to spread awareness of the disease but also to disseminate the fact that testing HIV positive certainly does not mean death, as so many people like me have proved, he says. "It is these positive messages that need to be spread strongly in awareness campaigns, which tend to focus more on use of condoms and having safe sex, which are anyway no less important," he says and

adds that he always stand as a testimony that HIV victims can live for long, if they get proper medical treatment.

After meeting members of Positive People Welfare society,' Kumar realized that he too can lead a normal life like others, with proper care and treatment. As a next step, he joined PPWS and started campaigning for HIV/AIDS.

Psycho-social support

The main issue, he feels, is psycho-social support, especially from doctors. In the Government Hospital, he claims that doctors hesitate to provide treatment for HIV positive patients. And he had fought successfully with the doctors seeking treatment for four cases.

"The awareness campaigns have certainly made a difference, but the situation is far from ideal. We have so many cases where people are leading healthy lives 12 to 15 years after being tested HIV positive," he says. Awareness should not only be created of HIV and AIDS but on the fact that though there is no cure for the virus, it is controllable because many spend their life's earnings with quacks, who promise miracle remedies.

"I have lost all my property and savings to quacks. I can live a comfortable life if I had my savings with me now," he says and adds that people should discuss about HIV and AIDS even at home.

Mixed emotions

Though all positives have mixed emotions of dejection and fear, they suffer for no fault of theirs; especially women, who contracts the virus from their husbands. Many nurture a grouse against the society, which is aggravated by the indifference of doctors and others.

Tirunelveli Positive People Welfare Society is an example of humanistic outreach. Getting involved can make a difference to many!

It is the story of true grit and determination of an HIV positive person. She acquired the 'dreaded' disease through her husband when she became pregnant second time shattering her dreams of conceiving a child and forcibly aborting the foetus.

She lead a life of recluse and isolation due to the mental agony of having acquired the 'dreaded' disease and even thought of dying with the disease unexpectedly. However, she took courage and approached the government hospital and found that hope for survival with the disease still existed with the medicines available at the ART centre which was distributed free of cost.

Selvi has today become a role model for others with the disease to survive without ART medicines and by eating healthy and nutritional food. She joined NGO called Positive Peoples' Welfare Society to provide counselling, medicines through the government ART centre and also assist by organising get-togethers and entertainment programmes to relieve stress. She urges philanthropists to help HIV positive people by providing nutritious food to improve their immune system which will help them to survive happily for a few more years.

Selvi is a crusader against ostracisation of HIV positive people in rural areas. However, she says that people still ostracise HIV positive people once they disclose their disease. Though majority people know that the disease is spread through sexual contact and other methods such as unsterilised syringes etc., but the general tendency is to isolate the affected person.

Research question 1: strategies in communicating HIV/AIDS

The interviewed PPWS members viewed HIV/AIDS communication in terms of their experience. In spite of giving awareness to the public about HIV/AIDS, we should also concentrate on the PLWHAs wellbeing.

Social worker of PPWS talked in length about the strategies they are using.

“Interpersonal communication is the efficient way to reach the public. The people living with HIV/AIDS are not expecting sympathy and also not interested in revealing past life. PLWHAs need the support, comfort, care and a listening heart. Face-to-face communication helps us a lot to sensitize the people. It helps to come out from the stigma. It also helps us to build rapport with the ICTC doctors and counselors. This eases our mapping process.”

A member of PPWS who is living with HIV/AIDS sensitizes people through public meetings.

“In our PPWS, we are sensitizing and mobilizing through Positive speak bureau. This bureau has active positive people who are ready to speak to the people about HIV/AIDS. We organize and attend meetings from PPWS. First, we will communicate about HIV/AIDS. Then we will ask them whether they have seen any PLWHA and expose our identity that we are PLWHA. First people will get shocked because they believe that PLWHAs will be bony and skeletal and they are not normal people. Our aim is to sensitize the public that PLWHAs are normal people but living with deficiencies. We effectively use public meetings to fight stigma and stereotypes.”

One of the initiator of PPWS in Tirunelveli shared his experiences. “Our main goal is to identify PLWHAs and extend care and support to them. For that

we need mapping. We utilize street theatres; collaborate with other NGOs in organizing health camps, exhibitions, and support group meetings. We use various games in those meetings to make the people to participate.”

Another member recorded his views that

“PPWS gives regular counseling to PLWHAs, care givers and support groups. We regularly meet PLWHAs who are undergoing ART (Anti-retro viral therapy) twice in a month. We take necessary steps to identify caregivers and arrange home based care for PLWHA. PLWHA need empathy and not sympathy. We also communicate the scientific facts of HIV/AIDS and sensitize the public. The people who attend the meeting pass on the message to others.”

Counselor of PPWS told us that “We encourage communicating opinion leaders. We frequently held meetings with community leaders, religious leaders and social workers. We also include self-help groups in our meeting. They pass on the message to their community. So it makes our job easier in disseminating HIV/AIDS communication.”

Research question 2: Challenges faced in communicating HIV/AIDS:

The community trainer told us that, “We enrolled 650 PLWHAs in our network. Among them only ten are earning 60,000 annually. Others are in severe poverty. Their socio-economic status is not very helpful for the treatment. They depend on us for treatment. Some NGOs are favoring CSWs with money and other goods for attending meetings. So they expect the same from us. But PPWS can offer only service and not satisfy commercial needs. We can also arrange some help to them.”

Respondents feel that PLWHAs are discriminated and marginalized by the society and it is very hard to digest when we are discriminated by our own family. It is really a big challenge to overcome stigma and discrimination.”

Process flow of PPWS Mapping

This is the 1st and main job of PPWS. They build rapport & make linkages with other NGO's, ICTCs, Hospitals etc, who are working under same stream. But the main problem of this stage is NGO's are not giving their full support. Another problem is Private Hospitals maintain confidentiality. So it's hard to identify Upper class people affected.

Identification of PLWHA

So, PPWS have to overcome these problems and identify respondents.

Peer Counseling, Enrollment and Consent

Then they will give Peer Counseling which is one of the effective methods, because the counselors are

also affected. Other processes are Enrollment and Consent.

Treatment Preparedness and Referral

Then the PLWHA will be sent for Treatment Preparedness and Referral.

Service Delivery

There are many services given by PPWS. Find the Caregivers and arrange for Home Based care for the PLWHA. PPWS Provides TAE (Teaching Adherel Education) trainings for PLWHAs and motivate Community mobilization / sensitization for the welfare of the PLWHAs. PPWS give Referral and linkages, Adherence Follow-up and formation of support groups are the other services of PPWS. Advocacy is the main work of PPWS. It includes informing their rights and also to community. Respondents are turned to Peer Educators.

Communication strategies of PPWS

PPWS Organizes health camps, Street theatres, Exhibitions, Participatory approaches & Group discussions combined with other NGO's. They also organize meetings for support groups, which brings in new respondents and make them to understand the services provided by counseling. Trainings are conducted for Peer educators. PPWS conducts Sensitizing meetings for religious leaders, school headmasters, and opinion leaders. Opinion leaders

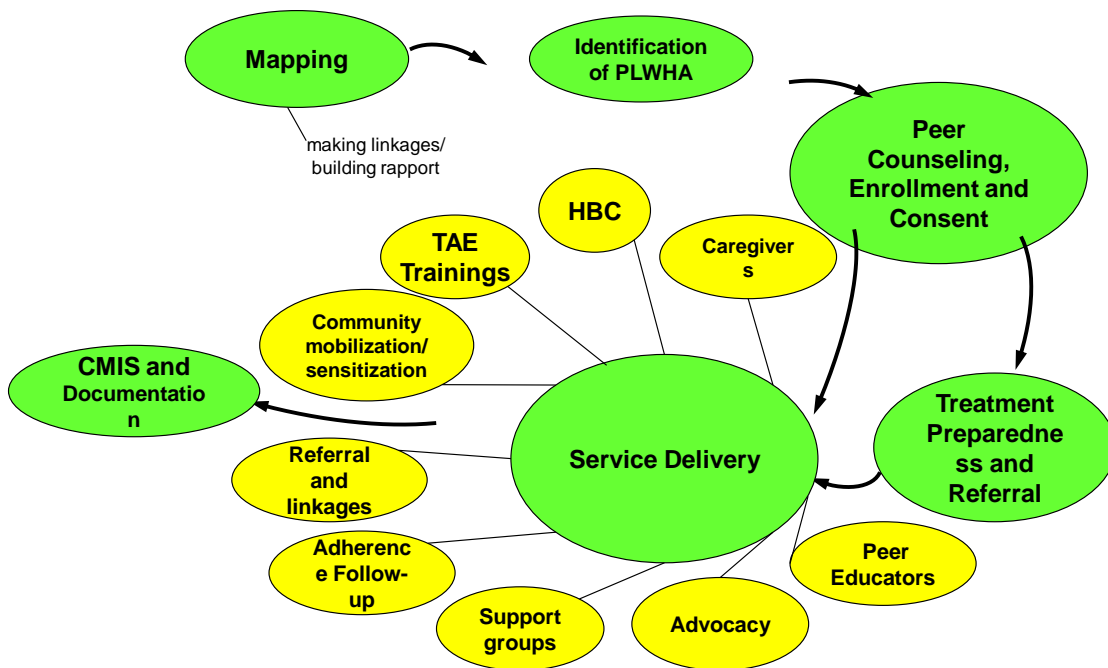
passes away the message to their followers and they act as gate keepers for identifying respondents in the respective areas and helps to motivate to create resources. Counseling and training are conducted for care givers, who are the care taker of particular respondents. Peer Educators are the PLWHAs who are involved in HIV/AIDS campaign and speak only before the suspected people. Positive Speak Bureau is another one significant concept of PPWS. Positive Speak Bureau consists of PLWHAs who are ready to expose their identity and speak before the public too.

DISCUSSION AND CONCLUSIONS

Summary

PPWS communication strategies include interpersonal communication, organizing health camps, public meetings, street theatres, counseling and training for care givers, sensitizing meetings for religious leaders, school headmasters and opinion leaders. PPWS faced difficulties in communicating HIV/AIDS. Involving positive people as volunteers is very useful in fighting stigma and stereotypes. Effective use of interpersonal communication helps to build rapport with the community and aid mapping. Also they concentrate more on gratifying the psychological needs of PLWHA by creating care givers and support groups. They find difficult to make the people understand the scientific facts of HIV/AIDS. Poverty, stigma and discrimination are the other challenges in communicating HIV/AIDS.

Process flow of GFATM/INP+/ACT Project -PWST+



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